

The DIPEX Charity, PO Box 428, Witney, Oxfordshire, OX28 9EU
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Launch of new online video resource for young people with arthritis

A new online resource that gives young people with arthritis a voice has been launched, giving them a chance to share their experiences and stories through video.

The new arthritis section of the award-winning youthhealthtalk.org website, which goes live on Friday, April 26, has been devised and created by researchers at the University of Oxford with financial support from medical research charity Arthritis Research UK.

Juvenile idiopathic arthritis affects around 15,000 children and young people in the UK, causing pain, disability, fatigue and long-term joint damage. Teenagers often struggle to overcome both the physical and emotional aspects of living with a long-term condition, and find it hard to cope with its impact on their education, social life and employment prospects.

Lead researcher Ben Simmons explains: “The aim of the project was to develop a section on the Youthhealthtalk website dedicated to young people’s experiences of living with arthritis.

“Information about arthritis in young people is often published online by academics, health professionals and the like, but we were concerned with developing an information resource based on the actual experiences of young people themselves. Videos are a great user-friendly way of explaining information and allowing the young people involved to speak out about their experiences.”

To that end researchers interviewed 40 young people primarily between the ages of 10 and 25 and 11 parents. Interviewees talked about their experiences of the medical side of the condition (symptoms, diagnosis, treatment, fatigue etc) as well as the impact arthritis can have on day-to-day life (eg education, work, college, relationships).

Most of the interviews were video recorded, with about 250 clips of young people and parents talking about their experiences, as well as a number of video diaries. A paediatric rheumatologist provides introductory clips to some of the medical topics.

Sixteen-year-old Kyrun Spraggs, who has had systemic onset juvenile idiopathic arthritis since the age of six, recorded a video diary for the website and says his physical and mental condition has greatly improved since being interviewed for Youthhealthtalk.

Although his arthritis is severe, requiring permanent medication and he has suffered from bouts of depression, Kyrun attends college and studies photography, and gets great support from his family and friends.

He says of his video diary: “I want to reach out to other people my age with the condition, and to tell them that there is always hope with new treatments.”

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The 18-month project has thrown up a number of findings:

- Many young people with arthritis are not diagnosed and treated quickly
- Many young people with arthritis lack confidence about their bodies because of medication such as steroids, or have phobias about long-term drug treatments
- Young people find emotional support from various sources such as health professionals, friends and family or by writing blogs or going on internet forums
- Arthritis affects the whole family not just the young person
- Schools need to be more aware about arthritis in young people
- The fatigue and exhaustion caused by arthritis are not understood by other people

“This new resource acknowledges these issues, and allows the young people with arthritis to get things off their chests,” adds Ben Simmons. “We hope the site will be used by health professionals and the public, but primarily patients, and that it goes some way to filling the current online information gap.”

Medical director of Arthritis Research UK Professor Alan Silman adds: “The internet has made a dramatic difference to how young people experience chronic health problems, and is now their first port of call for information and support.

“By mirroring their own experiences, we hope this new online resource made by young people with arthritis for their peer group will be helpful in ways that a more formal website run by well-meaning health professionals could never be.”

To access the arthritis section of the Youthhealthtalk website go to www.youthhealthtalk.org/young_people_with_arthritis/

ENDS

Youthhealthtalk

Youthhealthtalk.org, and its sister website Healthtalkonline.org, are experiential websites based on qualitative research led by experts at the University of Oxford and published by the DIPEX charity. The websites present personal experiences of over 75 different health conditions and are funded by a wide range of statutory bodies and charitable trusts. The websites are certified under the Department of Health’s Information Standard scheme.

Youthhealthtalk and Healthtalkonline receive over 2.5 million visitors annually. They are designed to provide support and information to patients, their carers, family and friends, doctors, nurses and other health professionals. Youthhealthtalk focuses specifically on the experiences of young people and includes research into illnesses such as cancer, epilepsy and diabetes as well as other health matters, including sexual health, drugs and alcohol and eating disorders.



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Arthritis Research UK

Arthritis Research UK is the leading authority on arthritis in the UK, conducting scientific and medical research into all types of arthritis and related musculoskeletal conditions. It is the UK's fourth largest medical research charity and the only charity solely committed to funding high quality research into the cause, treatment and cure of arthritis.

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